

## **Exploring and Defining Autism** **Through The Current Medical Model & The Lens of Neurodiversity**

### **Current Medical Model: DSM-V Diagnostic Criteria (Deficit-based)**

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understand relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers.

*Specify current severity: **Severity is based on social communication impairments and restricted, repetitive patterns of behavior.***

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypes, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment (e.g. apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

*Specify current severity: **Severity is based on social communication impairments and restricted, repetitive patterns of behavior.***

C. Symptoms must be present in the early developmental period (but may not become fully manifest until social demands exceed limited capacities, or may be masked by learned strategies in later life).

D. Symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

<https://www.cdc.gov/ncbddd/autism/hcp-dsm.html>

## The Lens of Neurodiversity

Autism is a genetically-based human neurological variant. The complex set of interrelated characteristics that distinguish autistic neurology from non-autistic neurology is not yet fully understood, but current evidence indicates that the central distinction is that autistic brains are characterized by particularly high levels of synaptic connectivity and responsiveness. This tends to make the autistic individual's subjective experience more intense and chaotic than that of non-autistic individuals: on both the sensorimotor and cognitive levels, the autistic mind tends to register more information, and the impact of each bit of information tends to be both stronger and less predictable.

Autism is a developmental phenomenon, meaning that it begins in utero and has a pervasive influence on development, on multiple levels, throughout the lifespan. Autism produces distinctive, atypical ways of thinking, moving, interaction, and sensory and cognitive processing. One analogy that has often been made is that autistic individuals have a different neurological "operating system" than non-autistic individuals.

According to current estimates, somewhere between one percent and two percent of the world's population is autistic. While the number of individuals diagnosed as autistic has increased continually over the past few decades, evidence suggests that this increase in diagnosis is the result of increased public and professional awareness, rather than an actual increase in the prevalence of autism.

Despite underlying neurological commonalities, autistic individuals are vastly different from one another. Some autistic individuals exhibit exceptional cognitive talents. However, in the context of a society designed around the sensory, cognitive, developmental, and social needs of non-autistic individuals, autistic individuals are almost always disabled to some degree – sometimes quite obviously, and sometimes more subtly.

The realm of social interaction is one context in which autistic individuals tend to consistently be disabled. An autistic child's sensory experience of the world is more intense and chaotic than that of a non-autistic child, and the ongoing task of navigating and integrating that experience thus occupies more of the autistic child's attention and energy. This means the autistic child has less attention and energy available to focus on the subtleties of social interaction. Difficulty meeting the social expectations of non-autistics often results in social rejection, which further compounds social difficulties and impedes social development. For this reason, autism has been frequently misconstrued as being essentially a set of "social and communication deficits," by those who are unaware that the social challenges faced by autistic individuals are just by-products of the intense and chaotic nature of autistic sensory and cognitive experience.

Autism is still widely regarded as a "disorder," but this view has been challenged in recent years by proponents of the neurodiversity model, which holds that autism and other neurocognitive variants are simply part of the natural spectrum of human biodiversity, like variations in ethnicity or sexual orientation (which have also been pathologized in the past). Ultimately, to describe autism as a disorder represents a value judgment rather than a scientific fact.

(Nick Walker, <http://neurocosmopolitanism.com/what-is-autism/>)

## **Five Steps Towards the Acceptance of Neurodivergent Populations**

*Adapted from Autistic blogger and advocate Nick Walker's Five Steps Toward Autism Acceptance: (<http://neurocosmopolitanism.com/five-steps-toward-autism-acceptance/>)*

### **1. De-pathologize neurodivergent people and neurodiverse populations**

There are many natural forms of human neurodiversity. For example, labeling “autism” as a “mental disorder” or a “disease” has no scientific basis, has no benefit for Autistic people or their families, and leads inevitably to stigmatization, shame, and marginalization. Blind people, Deaf people, and many other disabled people get the services and accommodations they need without being labeled as having mental disorders. We don't have to call autism a disorder or a disease to acknowledge that Autistic people are disabled and may require accommodations. Stop worrying about the latest changes to the DSM diagnostic criteria, and just remove autism from the DSM entirely, just like homosexuality was rightly removed years ago.

### **2. Use the language of diversity, not pathology.**

Language matters. The language that is used in talking about neurodivergent populations affects how these people are perceived — by themselves, by others, by society – and thus how they are treated. In an Autistic-friendly world for example, anyone speaking of autistics would observe the same linguistic conventions that civilized, non-bigoted people observe when speaking of any other social minority groups (e.g., African-Americans). You wouldn't say that an African-American “has negroism” or “suffers from blackness,” so don't speak of an Autistic person as “suffering from” autism.

### **3. Forget “normal” and check your privilege**

Recognize that when it comes to human diversity — including the diversity of minds — “normal” is a highly subjective, cultural construction. Recognize that there is no “normal” mind, and that conformity to the local conception of “normal” is in no way synonymous with health, well-being, or personal fulfillment – and is, in fact, often in direct conflict with those things. In nurturing the development of neurodivergent individuals, the goal of parents, educators, therapists, etc., should be to produce healthy, thriving, neurodivergent people, rather than neurodivergent people trained to stifle their true selves in order to pass as “normal.”

### **4. Equal protection under the law, broadly interpreted and strongly enforced.**

Recognize neurodivergent people as social minority groups, for example autistic people, and grant them the same legal protections that are (or should be) extended to ethnic minorities. Interpret those legal protections as broadly as possible, and rigorously enforce them. When an Autistic person is abused for acting Autistic, prosecute it as a hate crime. Individuals and organizations that speak of autism as a “disease” or “tragedy,” and that talk of “curing” it, should be prosecuted for hate speech and incitement to violence, just as if they were advocating a “Final Solution to the Jewish Problem.” Anyone involved in seeking or implementing prenatal tests for autism or any other sort of prenatal prevention of autism should be prosecuted in international court under the Genocide Convention, which classifies as genocide any attempt to prevent births within a targeted group.

### **5. Work for global peace and economic justice.**

Many non-autistic parents worry that if they don't subject their Autistic kids to extensive (and expensive) “treatments” to bring them closer to “normal,” the kids will never be able to take care of their own basic survival needs, and will end up in awful institutions or on the streets. This is an entirely legitimate concern. But the reason it's a concern is that we live in a world in which the forces of global capitalism have replaced the true spirit of community with an artificial sense of competition, isolation, and “every man for himself,” and in which all but the most wealthy are kept in a constant condition of anxiety and fear of scarcity. This is not the natural state of humanity, and not the way the world has to be. Instead of working so hard to change neurodivergent people in the name of helping them survive in a cruel world, why not work to make the world less cruel?

## **Recommended Resources**

### **Books:**

- *Aspergirls: Empowering Females with Asperger Syndrome* by Rudy Simone
- *Can I Tell You About Asperger Syndrome? A Guide for Friends and Family* by Jude Welton, Elizabeth Newton, and Jane Telford
- *Lost at School: Why Our Kids with Behavioural Challenges are Falling Through the Cracks and How We Can Help Them* by Ross W. Greene Ph.D.
- *Loud Hands: Autistic People Speaking* by Julia Bascom
- *Navigating College: A Handbook on Self Advocacy Written for Autistic Students from Autistic Adults* by The Autistic Self Advocacy Network, Melody Latimer, and Jim Sinclair
- *Neurodiversity: Discovering the Extraordinary Gifts of Autism, ADHD, Dyslexia, and Other Brain Differences* by Dr. Thomas Armstrong
- *Neurodiversity in the Classroom: Strength-Based Strategies to Help Students with Special Needs Succeed in School and Life* by Dr. Thomas Armstrong
- *Neurotribes: The Legacy of Autism and the Future of Neurodiversity* by Steve Silberman
- *The Real Experts: Readings for Parents of Autistic Children* by Michelle Sutton
- *The Autism Discussion Page On Anxiety, Behavior, School, and Parenting Strategies: A Toolbox for Helping Children with Autism Feel Safe, Accepted and Competent* by Bill Nason
- *The Autism Discussion Page On the Core Challenges of Autism: A Toolbox for Helping Children with Autism Feel Safe, Accepted and Competent* by Bill Nason
- *The Autism Discussion Page On Stress, Anxiety, and Meltdowns: Proactive Strategies for Minimizing Sensory, Social, and Emotional Overload* by Bill Nason
- *The Explosive Child: A New Approach for Understanding and Parenting Easily Frustrated, Chronically Inflexible Children* by Ross W. Greene Ph.D.
- *The Reason I Jump: The Inner Voice of a Thirteen-Year-Old Boy with Autism* by Naoki Higashida, and Tom Picasso
- *Uniquely Human: A Different Way of Seeing Autism* by Barry M. Prizant
- *What Every Autistic Girl Wishes Her Parents Knew* by the Autism Women's Network

### **Websites:**

- *Autism Experts: Take it From Us, We've Lived it!* - <https://www.aspergerexperts.com/>
- *Autistic Not Weird* - <https://autisticnotweird.com/>
- *Autonomous Press: Weird Books for Weird People* - <http://autpress.com/>
- *Foundations for Divergent Minds* - <https://www.divergentminds.org/>
- *Identity-First Autistic: Effecting Social Change Through Language* - <https://www.identityfirstautistic.org/>
- *Ido in Autismland* - <http://idoinautismland.com/>
- *Intune Pathways* - <https://www.intunepathways.com.au/>
- *Jeanette Purkis: Thoughts on all Things Autism and Mental Health* - <https://jeanettepurkis.wordpress.com/>
- *Lives in the Balance* - <https://www.livesinthebalance.org/>
- *Michelle Sutton Writes* - <https://michellesuttonwrites.com/>
- *Musings of an Aspie* - <https://musingsofanaspie.com/>
- *My Autistic Dance* - <https://myautisticdance.blog/>
- *Neurocosmopolitanism: Nick Walker's Notes on Neurodiversity, Autism, and Cognitive Liberty* - <http://neurocosmopolitanism.com/>
- *Neurowonderful* - <http://neurowonderful.tumblr.com/>
- *Ollibean: Neurodiversity* - <https://ollibean.com/category/neurodiversity/>
- *Respectfully Connected* - <http://respectfullyconnected.com/>
- *Special Books by Special Kids: Normalizing the Diversity of the Human Condition* - <https://sbsk.org/>
- *Sue Larkey* - <https://suelarkey.com.au/>

- *The Autism Discussion Page* - <https://www.facebook.com/autismdiscussionpage/>
- *Thinking Person's Guide to Autism: Autism News and Resources from Autistic People, Professionals, and Parents* - <http://www.thinkingautismguide.com/>
- *Tony Attwood* - <http://www.tonyattwood.com.au/>
- *Unstrange Mind: Autistic Author, Artist, Advocate, and Speaker* - <http://unstrangemind.com/>
- *We Are Like Your Child* - <http://wearelikeyourchild.blogspot.ca/>

#### Videos:

- *Animated Explanation of Autism* - <https://www.youtube.com/watch?v=6fy7gUlp8Ms>
- *Ask an Autistic: Amythest Schaber* (youtube channel) - <https://www.youtube.com/channel/UC9Bk0GbW8xqvTgQlheNG5uw>
- *Asperger's Syndrome Explained for Children* (Arthur clip) - <https://www.youtube.com/watch?v=s9eATBV-lq&t=1s>
- *Autism – How My Unstoppable Mother Proved the Experts Wrong: Chris Varney at TEDxMelbourne* - <https://www.youtube.com/watch?v=T1HQKB2txgY>
- *Autistic Identity and the Neurodiversity Paradigm: Nick Walker 2014* - <https://www.youtube.com/watch?v=s0TrcbUyiSM&feature=youtu.be>
- *Marvelous Max – Autism Awareness for Kids* - [https://www.youtube.com/watch?v=wc77MksM\\_2c](https://www.youtube.com/watch?v=wc77MksM_2c)

#### Specific Articles:

- *A Behavior Plan for Parents of Newly Diagnosed Autistic Children* - <http://autisticimestwo.blogspot.ca/2015/12/behavior-plan-for-parents-of-newly.html>
- *Actually Autistic Blogs List* - <https://anautismobserver.wordpress.com/>
- *"Affected" by Autism* - <https://everydayaspie.wordpress.com/2016/08/09/affected-by-autism/>
- *After An Autism Diagnosis: 13 Necessary Next Steps for Parents* - <http://www.thinkingautismguide.com/2017/03/after-autism-diagnosis-13-necessary.html>
- *Awareness Vs. Acceptance* - <https://fullmetalheart.com/index.php/2017/04/04/awareness-vs-acceptance/>
- *Behavior Modification Does Work, But...* - <https://michellesuttonwrites.com/2017/04/07/behaviour-modification-therapy-does-work/>
- *How 'Autism Warrior Parents' Harm Autistic Kids* - <https://theestablishment.co/how-autism-warrior-parents-harm-autistic-kids-6700b8bf6677>
- *I Might be on the Autism Spectrum. Now What?* - <http://www.myspectrumsuite.com/might-autism-spectrum/>
- *More Problems with Functioning Labels* - <https://ollibeau.com/problems-functioning-labels/>
- *My Child is Autistic: Now What?* - <https://un-boxedbrain.com/2016/12/my-child-autistic/>
- *Neurodiversity: A Person, A Perspective, A Movement?* - <https://the-art-of-autism.com/neurodiverse-a-person-a-perspective-a-movement/>
- *My Needs Are Not Special* - <https://michellesuttonwrites.com/2016/05/26/my-needs-are-not-special/>
- *Say the Word: Disabled not "Special Needs"* - <https://erinhuman.com/2016/02/16/stop-saying-special-needs/>
- *Throw Away the Master's Tools: Liberating Ourselves from the Pathology Paradigm* - <http://neurocosmopolitanism.com/throw-away-the-masters-tools-liberating-ourselves-from-the-pathology-paradigm/>
- *Tony Attwood: What is Asperger's Syndrome?* - <http://www.tonyattwood.com.au/about-aspergers/what-is-aspergers>
- *Understanding the Spectrum - A Comic Strip Explanation* - <https://the-art-of-autism.com/understanding-the-spectrum-a-comic-strip-explanation/>
- *When Clinicians Attribute All Psychiatric Symptomatology to the Autism* - <https://ollibeau.com/mental-health-therapy-autistic-client-only-autism/>

## Autism in Girls:

- *Asperger Syndrome in Girls and Women: Keeping Up Appearances and Missed Diagnosis* - <https://taniaannmarshall.wordpress.com/2013/03/15/asperger-syndrome-in-girls-and-women-keeping-up-appearances-and-missed-diagnosis/>
- *Aspien Girl* - <http://www.aspiengirl.com/>
- *Aspienwomen: Moving Towards an Adult Female Profile of Autism/Asperger Syndrome* - <https://taniaannmarshall.wordpress.com/2013/03/26/moving-towards-a-female-profile-the-unique-characteristics-abilities-and-talents-of-asperwomen-adult-women-with-asperger-syndrome/>
- *Autism Women's Network* - <https://autismwomensnetwork.org/>
- *Diagnostic Tests for Autism May Miss Many Girls* - <https://spectrumnews.org/news/diagnostic-tests-for-autism-may-miss-many-girls/>
- *Everyday Asperger's* - <https://everydayaspergers.com/>
- *Jennifer O'Toole* - <https://www.jenniferotooleauthor.com/>
- *Tony Attwood: Girls and Women Who Have Asperger's Syndrome* - <http://www.tonyattwood.com.au/about-aspergers/girls-and-women-who-have-aspergers>
- *The Art of Autism: Females & Aspergers, A Checklist* - <https://the-art-of-autism.com/females-and-aspergers-a-checklist/>
- *Yellow Lady Bugs* - <http://yellowladybugs.com.au/>